

CA1
SW
-80W68
GOVT

31761 117100214

Brief to the Special Committee
on the Disabled and the Handicapped

WOMEN WITH HANDICAPS

**Canadian Advisory Council
on the Status of Women**

Box 1541 Station B, Ottawa K1P 5R5

**Conseil consultatif canadien
de la situation de la femme**

C.P. 1541 Succ. B, Ottawa K1P 5R5



CA1
SW
-80W68

Brief to the Special Committee
on the Disabled and the Handicapped

WOMEN WITH HANDICAPS



**Canadian Advisory Council
on the Status of Women**

Box 1541 Station B, Ottawa K1P 5R5

**Conseil consultatif canadien
de la situation de la femme**

C.P. 1541 Succ. B, Ottawa K1P 5R5

Brief to the Special Committee
on the Disabled and the Handicapped

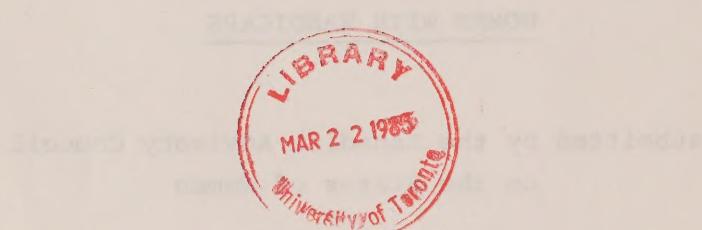
WOMEN WITH HANDICAPS

submitted by the Canadian Advisory Council
on the Status of Women

1980

based on a background paper
written by Laura Weintraub
with the assistance of Catherine MacLeod, Pat Schulz
and Brian Flack

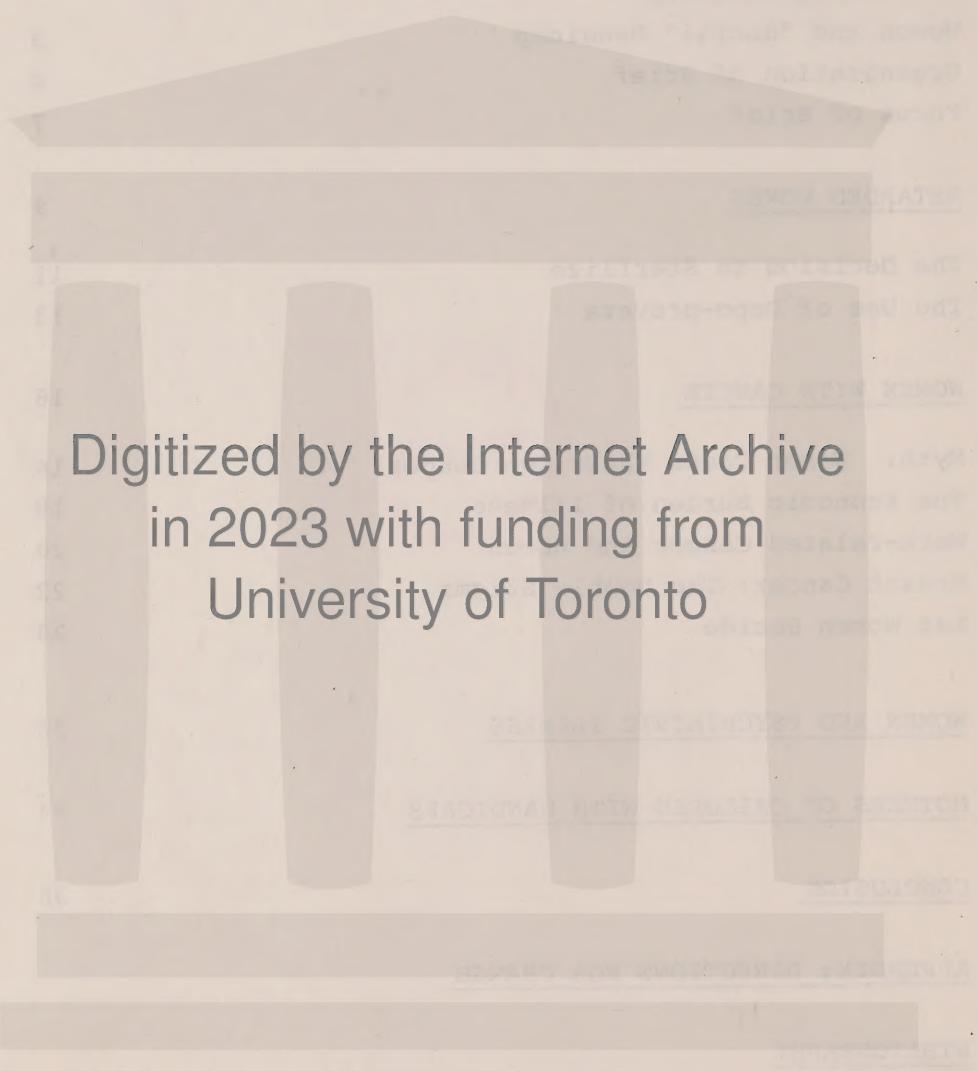
enrichments, including new or taken
acquisitions, will be included in the



6521

TABLE OF CONTENTS

	<u>Page</u>
<u>INTRODUCTION</u>	1
Redefining Handicap	1
Women and "Social" Handicap	3
Organization of Brief	4
Focus of Brief	7
 <u>RETARDED WOMEN</u>	 9
The Decision to Sterilize	11
The Use of Depo-provera	13
 <u>WOMEN WITH CANCER</u>	 16
Myth: Women Cause Their Own Cancer	16
The Economic Burden of Illness	18
Work-related Cancer and Women	20
Breast Cancer: The Double Stigma	22
Let Women Decide	23
 <u>WOMEN AND PSYCHIATRIC ILLNESS</u>	 28
 <u>MOTHERS OF CHILDREN WITH HANDICAPS</u>	 34
 <u>CONCLUSION</u>	 38
 <u>APPENDIX: DIRECTIONS FOR CHANGE</u>	
 <u>BIBLIOGRAPHY</u>	



Digitized by the Internet Archive
in 2023 with funding from
University of Toronto

<https://archive.org/details/31761117100214>

INTRODUCTION

Individuals with handicaps live with the stigma that they are defective, infectious, subhuman, a punishment upon families and a eugenic threat to the purity of our nation. Women also are believed to be weaker members of our society on the basis of physical differences because they have less striated muscle than men, they menstruate, have menopause and bear children. This brief examines the impact of these combined attitudes and the practices which result from such beliefs upon individuals who are women and who are handicapped.

Redefining Handicap

The common conception of people with handicaps is limited to individuals with visible, physical disabilities; the blind, people who limp, who have an artificial limb, a crutch, a wheelchair. The visibly handicapped do indeed comprise an important group of people with handicaps, but the tendency of policy-makers, professionals and the general public is to focus only on visible handicaps.¹ This narrow definition creates the illusion that community associations or government agencies are handling the problems of the handicapped quite effectively and that charities and other special groups exist for the benefit of most of the disabled.²

¹The recent publication by Health and Welfare of Disabled Persons in Canada, Ottawa: Supply and Services Canada, 1980, reinforces this narrow definition of handicap.

²For a discussion of a range of public attitudes toward disability, see W. Wolfensberger, The Principle of Normalization in Human Services, Downsview, Ont: National Institute on Mental Retardation, 1972.

As a result, the scope of policy reform related to the handicapped is limited, public concern is minimized, and the needs of a large number of Canadians with handicaps are overlooked.

The CACSW, in view of the current official and unofficial emphasis on visible handicaps, and the anticipated high representation of advocates for the visibly handicapped to the Special Committee on the Disabled and the Handicapped, has chosen to focus in this brief on less visible disabilities . . . disabilities which may not immediately be thought of as handicaps and yet which isolate and constrain as effectively as blindness or loss of a limb.

Recently, the popular definition of handicap has been slightly extended by the media to include less visible handicaps through the use of sign language for television viewers who are deaf, through media fund-raising campaigns which familiarize the public with the physical appearance of a child with Down's Syndrome, and through coverage of attempts to end job discrimination against individuals with epilepsy.

But even this expanded definition doesn't go far enough. There are also those handicaps less frequently visible, which may cause only social awkwardness and which are usually not considered real handicaps: the healthy-looking teenager on the bus who clutches a Snoopy lunchbox and chatters away in a friendly fashion to unwilling strangers; the elderly neighbour who lives in a seedy apartment, never has visitors and never verbally communicates; the adult wearing torn runners and too many overcoats, trudging through the snow carrying shopping bags; the chronically depressed suburban housewife; the middle-aged woman who for years will be living with, but dying of, cancer - to name only a few.

And then there is another group with a different kind of limited visibility handicap - the people with recognized handicaps who are kept totally invisible - segments of our population, some with visible, some with semi-visible handicaps, which are kept segregated, institutionalized and permanently removed from the public eye. These "others" lead strange, faraway lives at public expense.³ Such Canadians have no voice in the resolution of their handicaps and the level of public concern about them is low. The common expectation is that for all these individuals, someone in authority is intervening on their behalf when it is necessary. The effectiveness of the existing intervention and the concerns of these groups must also be considered when we speak of "handicaps".

Women and "Social" Handicap

A lack of choice, stigmatization on the basis of physical attributes, and isolation similar to that experienced by most handicapped people, has also been experienced by many women who are not defined as handicapped. Women in our society are generally disadvantaged relative to men, as the handicapped are. disadvantaged relative to the non-handicapped. Their roles are limited, they receive fewer rewards, and their choices are assumed to be constrained by their female physical attributes.

The causes of their disadvantage, like many of the handicaps in our society are invisible or disguised, and their disadvantage is not always apparent in individual cases, but the long-term and aggregate results are very concrete and visible.

³A classical study of the experience of the institutional inmate is E. Goffman's Asylums: Essays on the Social Situation of Mental Patients and Other Inmates, New York: Doubleday, 1961.

The examples abound. Women have to work eight days to earn the same money that men earn in five. About three times as many women as men over 60 and alone, live in poverty. Only 4.9% of working women are in managerial or administrative positions. The unemployment rate of women is 9.6%, compared to 7.6% for men.⁴

Women are restricted, as are the handicapped of both sexes, in the options and rewards which society offers. Women more than men are victims of exploitation and violence. Wife battering for example accounts for 75% of family violence, husband battering for only 2%.⁵ For these reasons, women as a group can be said to be "socially" handicapped. It is obvious then, because of the position of women and the position of people with handicaps in our society, that women with handicaps are doubly disadvantaged.

The Organization of the Brief

To emphasize the double disadvantage frequently suffered by women with handicaps, within a broad definition of handicap, the authors of this brief have chosen to detail some specific problems of women with three types of handicap: women who are retarded, women with cancer, and women diagnosed as having a psychiatric illness.

These specific handicaps were chosen for two reasons. First, they fall within the realm of semi-visible, or invisible handicaps. Second, the restraints imposed by these

⁴ Facts taken from CACSW Fact Sheets: Women and Work and Women and Aging, published in 1979.

⁵ L. MacLeod, Wife Battering is Every Woman's Issue: a summary report of the CACSW consultation on wife battering, March 5-7, 1980, Ottawa: CACSW, 1980.

disabilities and the professional treatment approach usually applied to these disabilities, are magnified by the restraints women experience in our society through economic, role or status inequities and related expectations regarding their physical characteristics and capabilities. Women with these disabilities are likely to be disproportionately at risk relative to men with the same disabilities, both in the quality and type of care they receive, and in their potential for choice over treatment alternatives.

It must be emphasized that the selection of these three groups is an arbitrary one taken from a long list of double hazard, and that these particular groups are put forward as a mere example of the impact of double hazard. Such a selection is necessary because of the constraints of time and formal submissions, but does not deny the necessity for concern with other groups of women with handicaps including such groups as: old women who are physically and financially dependent,⁶ women with

⁶ See, for example, the study by L. Dulude, Women and Aging, A Report on the Rest of Our Lives, Ottawa: CACSW, 1978. It is of relevance to note the following indicators of female poverty in Canada: 3 out of 4 single, widowed or divorced women over 70 had annual incomes under \$5,000 (1977) . . . About 333,000 single, widowed or divorced women over 60 live in poverty - three times the number of men in the same circumstances (1977) . . . Even with the Government's old age pension, 3 out of 5 single, widowed or divorced women over 65 live in poverty (1977). Company pensions don't help many women; 4 out of 5 single, divorced or widowed women over 65 received no income from private pensions . . . In 1976 the elderly were less than 10% of the population and the government paid about 5% of the national income for their public pensions and health care. By 2031, it is predicted that there will be even less tax money spent on each older Canadian. Although 20% of the population will be over 65, we will probably spend only 8% of our national income on their public pensions and health care. Taken from CACSW Fact Sheet 2, Women and Aging.

alcohol and drug dependence,⁷ women with multiple handicaps, women with a chronic illness or handicapped women living in rural or isolated places.

In this brief, some of the special problems of women who are retarded or have cancer, or have been diagnosed as being mentally ill, will be briefly examined. The assumptions and practices of the social and health delivery systems which these women use, will be reviewed, and an attempt will be made to determine how the disability, public perceptions, attitudes and service deliveries intertwine in maintaining double jeopardy for women with handicaps. Finally, the difficulties faced by women who are mothers of the handicapped, will be introduced.

⁷For literature discussing the complex problem of women excluded from alcohol and drug dependence treatment, see: J. Fraser, The Female Alcoholic, Toronto: Addiction Research Foundation of Ontario, 1976; J. Dowsling and A. MacLennan, eds., The Chemically Dependent Woman, Toronto: ARF, 1978; and A. MacLennan, ed., Women: Their Use of Alcohol and Other Legal Drugs, Toronto: ARF, 1976.

The Special Committee on the Disabled and the Handicapped may wish to address itself to the extensive problem of women excluded from employment-based preventive and treatment programs for alcoholics in addition to community-based programs. The employment-based exclusions exist not only in government-sponsored programs and departments, but also in industry, and attention to these matters is urgent.

The Focus of This Brief

Four points will be repeated throughout this brief, and are summarized below for emphasis.

- 1) The present conception of handicap held by policy-makers and professionals, based on a visible definition of handicap, is restrictively narrow. Programs for treatment and support, based on this definition, provide inadequate economic, educational and social support, and so place punishing burdens on the handicapped and their families.
- 2) Women with handicaps are doubly disadvantaged. They are disadvantaged first because of their specific disabilities and second because of the economic status and role inequities suffered by all women. The educational, residential, vocational, medical, legislative, and social inequities experienced by all handicapped people frequently affect women with handicaps more than men with handicaps.
- 3) Women are the primary caretakers of people with handicaps, both formally in their roles as nurses, physiotherapists, doctors and social workers, and informally as the mothers, wives and daughters of disabled family members. In spite of the importance of this role, social and financial support for women who care for the handicapped "unofficially" is virtually non-existent and even "official" workers are often poorly rewarded economically.⁸ Women who care for the handicapped "unofficially" are

⁸ A nurse with 14 years of education earns less than a delivery man; a female nurse's aid earns only \$184.00 a week compared to her male counterpart, an uncertified orderly who earns \$195.00. CACSW Fact Sheet: Women and Work, 1979.

severely socially handicapped by the enormous responsibility of caring for children and other relatives who are physically and/or mentally handicapped, in a society which offers almost no support or assistance.

- 4) People with handicaps should to the greatest extent possible, be given a real, informed choice over treatment alternatives and lifestyle options. Too often because the disabilities suffered by the handicapped are exaggerated or generalized by professionals and the general public, people with handicaps are needlessly treated like "second-class citizens." An effective concern with women who have handicaps, must include, above all, a commitment to affirm their dignity and integrity.

RETARDED WOMEN

Approximately three percent of the Canadian population has been diagnosed as mentally retarded. Taking a conservative estimate, then, we are speaking of about 689,000 men and women who are vulnerable to a wide variety of deprivations and exclusions because of the characteristics of their handicap and the stigma attached to these characteristics.⁹

⁹ The Canadian Association for the Mentally Retarded reports in Questions and Answers About Mental Retardation, 1979, the following estimates of Canada's mentally retarded population, based upon the 1976 Canada Census and World Health Organization summaries of international incidence studies:

Total Pop.	Retarded Population	Level of Severity			
		Mild	Moderate	Severe	Profound
22,992,604	689,778	88%	7%	4%	1%

The National Institute on Mental Retardation has pointed out that the three percent figure is the number of people who at some time in their lives will be labelled as retarded.

Of the three percent group, it is difficult to ascertain what proportion is confined to institutions. For example, Statistics Canada figures for Patient Movement in institutions identifies 8,011 females and 10,919 males as inmates in Canadian institutions for the retarded on January 1, 1977. These figures do not include, however, the retarded people who are living in homes for special care, homes for the aged, or special nursing homes. The estimate for Ontario alone is that 3,000 mentally retarded people are in (inappropriate) nursing homes. Nor do the figures include mentally retarded people who are in public and federal mental and psychiatric hospitals, which sometimes have wards or units housing the retarded, and are not always included in the Statistics Canada reports.

Many of these Canadians will be excluded from playgrounds, daycare and nursery schools. Many will be excluded from local schools, from daycamps, from youth groups, from clubs, from public transportation, from pinball arcades, from places of worship, and from concerts and movies. Many will be excluded from work, from access to any voluntary selection of birth control, from friendship, from privacy, from dating, and from marriage. Many of these Canadians will be excluded from legislative and court protection, from day-to-day decision-making, from neighbourhoods, and from valuing themselves. Many will be confined to institutions at some time in their lives, and will thereby be excluded from life "on the outside".

Both women and men who are retarded experience these exclusions. The impact upon retarded women however, must be specifically examined because of their particular and multiple vulnerabilities.

The retarded woman is doubly vulnerable because she is frequently subjected to differential treatment based on assumptions made by the professionals with whom she is in contact and by other community members, about the proper role of women in society, and the proper management of her bodily functions.

For example, in community schools and vocational centers for the retarded across the country, retarded girls and women are encouraged to adopt a more passive role than retarded men, and are encouraged to take particular interest in grooming and hygiene. Retarded women are taught to appear as normatively attractive females, but conversely they must act as passive, de-sexualized, eternal children. They are subjected first to the

restrictions placed on retarded people generally and then these restrictions are magnified by the additional restrictions placed on them as women. Two issues which demonstrate the special problems of retarded women are the currently controversial issues of sterilization of the retarded, and the use of depo-provera to suppress the menstruation of institutionalized, retarded women.

The Decision to Sterilize

The issue of sterilization of the retarded is an extremely complex one. A comprehensive discussion or an attempt at solution of the many aspects of the problem is beyond the scope of this brief. However, certain key principles merit a central place in the debate, in the interests of women who are retarded.

Hundreds of women - and some men - are sterilized without rigorous protection of their right to exercise the full degree of informed consent of which they are capable, and without adequate information or serious consideration of the physical side effects, medical options and human implications of such decisions. For example, 308 retarded people under age 18 were sterilized in Ontario in 1976, solely on parental consent, before a temporary provincial moratorium was called. All but fifty of these were girls, as vasectomy is not practiced as freely. In Québec, it was reported that "more than 500 retarded Québeckers, many of them youngsters, were sterilized between 1976 and 1978."¹⁰

¹⁰ Figures and quotes reported in "Retarded should be sterilized, parents say", The Globe and Mail, March 25, 1980.

It is undeniable that parents of retarded children who choose to keep their children out of institutions are frequently faced with a very difficult problem when their children reach puberty. Promiscuity, sexual exploitation and pregnancy are very real concerns. The plight of the parents must not be treated lightly and their decision to keep their children in the community should be applauded.

At the same time however, the decision to sterilize retarded adolescents should be weighed very carefully, considering: the many other birth control options currently available, the lack of complete knowledge of the effects a total hysterectomy may have when performed on a young girl, and the ability of the retarded girl to learn to manage hygiene during menstruation, or to learn to use the birth control method most appropriate for her.

Sterilization must not be used as a "short-cut to replace time-consuming social and behavioral services."¹¹ Parents as well as their retarded children need the most complete information available on the options open to them. Parents also need support services including counselling to help them deal with the sexuality of a retarded child. These services might be offered through existing community family planning centres or through community mental health clinics.

¹¹P.J. Accardo and A.J. Capute, The Pediatrician and and the Developmentally Delayed Child, Baltimore: University Park Press, 1979, pp. 184 and 185.

While the plight of the parents of retarded children must be responded to with seriousness, compassion and social service support, the rights of the retarded must not be forgotten in the process. Parents are not always the best advocates for a retarded child. Disinterested third parties, possibly from community mental health clinics, family planning centres or sexual counselling centres, should be consulted, particularly when the parents' choice of birth control for their retarded child is sterilization.

Similarly, within institutions, safeguards are needed to prevent the use of sterilization primarily to avoid teaching retarded women to cope with menstruation. Of course, the degree of retardation is a factor in this decision, but in a recent clinical textbook for pediatricians, the authors suggest that "with minimal nursing supervision, the care of menstrual flow is less complicated than toileting."¹²

The Use of Depo-provera

As a further demonstration of the potential victimization of retarded women when convenience is placed first, in at least one province, institutions find it more convenient and efficient to administer a drug called Depo-provera, rather than to teach retarded women to use tampons. Approximately 225 mentally retarded women in Ontario institutions are known as being treated with Depo-provera.¹³ This drug suppresses menstruation and

¹² Ibid., p. 185.

¹³ Ontario Legislature Debates, 4th Session, 31st Parliament, June 2, 1980, Standing Committee on Social Development, No. S-19, p. S572.

is tightly controlled or highly controversial in other countries.¹⁴

Depo-provera is given by injection every three months, and slowly releases the hormone progestin. It is used to inhibit ovulation, to treat menstrual disorders, to suppress menstruation, and for the treatment of cancer of the uterine lining (endometrial cancer) and cancer of the uterus. The drug has only been available about a decade, so long-term risks for women have not been established. The reported short-term side effects can include spotty bleeding, edema, depression, reduction of breast size and growth of facial hair.¹⁵

Currently it is impossible to ascertain how many women both retarded and non-retarded, in what places, are receiving Depo-provera, and for what purposes.. Medical

¹⁴ Depo-provera has been linked experimentally in the United States as a carcinogen in beagle dogs (development of breast tumours, although there is recent medical comment that beagles may not be useful test animals because of exaggerated propensity to breast cancers) and Rhesus monkeys (endometrial cancer development). The U.S. Food and Drug Administration refused to approve the drug for distribution in the U.S., while allowing its export to other countries. The drug is particularly useful in cultures and countries where husbands/families actively disapprove or prohibit the woman's access to birth control, and family planners in third world countries have argued for its continued use because the dangers of the drug are likely outweighed by dangers to women's health through no birth control.

¹⁵ C. Levine, "Depo-provera and contraceptive risk: A case study of values in conflict", in The Hastings Centre Report, August 1979. Further information on recent controversy about Depo-provera and its effects are reported in The Globe and Mail, July 23, 1980, p. 12 and Boston Women's Health Book Collective, Our Bodies, Ourselves, revised edition, New York: Simon and Schuster, 1979, pp. 150-151.

accountability has not been demanded on this issue because health care and drug prescription are overseen through licensing and ethical codes established by non-accountable colleges of physicians and surgeons in each province.

The use of Depo-provera should be closely monitored and controlled so that, like sterilization, it is not used only as a short-cut when other viable alternatives, including instructing the retarded in hygiene, are available.

WOMEN WITH CANCER

The word "cancer" has the power to strike fear in the heart of every person and while much of that fear derives from the knowledge that the disease is frequently fatal, a portion comes from the realization that to have cancer is to be sentenced to a kind of living death. Cancer patients are often ostracized by friends, discriminated against in the work place, lack personal involvement in their medical treatment, do not receive support services or psychological, nutritional and physiotherapy assistance, and may not even have the choice of where and how to die.

Twenty-one percent of all deaths in Canada are cancer deaths, and incidence figures are higher than mortality figures.¹⁶ The implications, then, are severe for Canadian women and men, but cancer does place women in some situations of double jeopardy not experienced by men. A few of the specific dilemmas of women with cancer are discussed below.

Myth: Women Cause Their Own Cancer

The myths that abound about cancer contribute to wholesale confusion.¹⁷ Cancer is believed by some

¹⁶ Statistics Canada, Perspectives Canada III, Ottawa: 1980 (Catalogue No. 11-511E). Additionally, Table I, Appendix of this CACSW brief indicates incidence and mortality statistics for all cancers in Canada in 1976, by age and sex.

¹⁷ In a study of widows' adjustments following their husbands' cancer deaths in Toronto hospitals, M.L.S. Vachon et al. report that: "Lack of information about cancer as a disease was a problem. Some widows resented caring for their husbands because they were certain his disease was contagious. Others were furious at the Canadian Cancer Society for slogans such as 'cancer can be beaten' when their husband had died. Taken from "The final illness in cancer: the widow's perspective", C.M.A. Journal, Vol. 117, No. 10, 1977, p. 1154.

to be contagious. Radiated patients are thought to be radioactive and contaminated. In addition to these general myths, specific myths have developed about women with cancer. It is suggested that the patient somehow brought the disease on herself through too much sexual activity, not enough sexual activity, not having children, having too many children, having children at the wrong age, nursing her children, not nursing her children, lack of a positive outlook, too much stress, too much repression or by being too weak or self-indulgent. These myths may be used to justify avoiding or abandoning the person with cancer.¹⁸

Public perceptions induced by mythology may be further confused by national campaigns that convey the simplistic message that early treatment can provide cure. This message can increase the responsibility and guilt the cancer victim feels about his/her disease. The slogan "Cancer can be beaten" and the commercials showing tennis playing cancer patients, deny the reality of widespread public experience of the disease. A more honest advertising policy on the part of the Canadian Cancer Society would perhaps suggest this: "Cancer is assuming what appears to be epidemic proportions due to the aging population and other partly known factors which require research and funding to explore. No simple cures have been found.

¹⁸ A full exploration of the myths of cancer is developed by S. Sontag in Illness as Metaphor, New York: Random 1977, in which she compares the expression of beliefs about tuberculosis in the last century with those about cancer in this century. She also comments that the medical and community believers of such myths "manage to put the onus of the disease on the patient and not only weaken the patient's ability to understand the range of plausible medical treatment but also, implicitly, direct the patient away from such treatment." (p. 46).

Avoidance of smoking, early detection, and treatment, do give patients a longer life and better health, but ultimately, the disease is a fatal one in most cases." Anything less than these statements is a denial of the reality, and an undercutting of the fear and grief that many Canadians experience.

The Economic Burden of Illness

The reality of cancer also includes severe economic burdens. As documented in the introduction to this brief, women earn less and are more likely than men to live in poverty. Further, because women tend to have low level jobs with little time flexibility, because women have the primary responsibility for child care in a society where daycare is inadequate and expensive, the financial and time constraints of serious illness pose particular problems for women.

Cancer patients are usually treated in clinics specializing in cancer because the necessary equipment, knowledge and personnel are there. Such centres are also frequently overcrowded.¹⁹ For out-patients this means long waits for treatment; waiting for several hours is not uncommon. When one spends the day waiting first at Blood, then at X-Ray, then at Records, then at the Doctors' Clinic, and then at Radiation, and finally is asked to return the next day because one or two of these services were over-booked and/or under-staffed, treatment becomes an intolerable ordeal. When one realizes that cancer is a long term disease with visits to clinics sometimes required every day for weeks, or once or twice a month for years, waiting becomes almost a full-time occupation. Quite apart from the economic effects, it leaves cancer

¹⁹ The authors of this brief were unable because of time and cost constraints to take an inventory of the Cancer clinics across Canada and the number of patients they treat. Detailed national statistics are not currently available.

atients with the feeling that their time and their other pursuits are irrelevant. Such a morbid and enforced preoccupation is damaging. It could also be easily avoided by a strong resolve to provide adequate cancer treatment facilities for Canadians, easily accessible to working people, to ensure the patient an identity beyond that of a cancer victim.

These problems are exaggerated not only when the patient works, but also when she/he is living far from treatment centres. The patient may have to travel miles each time, or make arrangements for staying at clinics. When the patient is very ill the added worry about transportation costs, only paid for in cases of proven hardship, may preclude the support of the family, whose accommodation is yet another economic burden for those whose incomes may already be jeopardized by their illness.

When the patient is a woman who is elderly and alone, or a mother, or a single parent, the problem of obtaining a suitable homemaker may loom large. Single parents, particularly have a difficult time arranging for good quality alternative childcare, both over the short and long term. While local Cancer Societies sometimes assist poor women by obtaining baby sitters or homemakers, the emotional (and often financial) worries remain serious problems to be sorted out by a woman who may be isolated, without community support and unable to obtain professional help.²⁰

²⁰ Despite the commendable efforts of hundreds and hundreds of volunteers who directly assist cancer patients through the coordinating auspices of the provincial and national Cancer Societies, psychological supports are not easily available for cancer patients, and specific supports that women with cancer may need are rare indeed. Furthermore, the supports that do exist may be weakened when professionals unconsciously or explicitly adhere to the myths about "cancer personalities".

Often obscured is the direct question of economic burden and this must not be minimized. First, loss of income from illness is a problem generally, for women and men, but it may be a double hazard for women. Since many income replacement plans (including federal government plans such as Unemployment Insurance and Canada Pension) provide for a percentage of previous earned income, women are more likely to live in poverty when ill than men.²¹ More women than men are attached to the work force on a part-time basis, either directly or indirectly because of their child-bearing, child-rearing and child-care functions. Women are therefore more likely to constitute a secondary labour market and are more likely to be in occupations which are not unionized and offer poor or no fringe benefits.²²

Work-related Cancer and Women

Women are exposed to different carcinogens than men due to occupational differences. Many female-dominated occupations have been under-researched. As a result, cancer, when it appears in women, may be attributed to sexual behaviour, smoking habits, worker age, or factors other than the work environment, and no action is taken to identify and reduce carcinogenic agents in the work place.

²¹ See, for example, the following CACSW documentation:
a. Recommendations on Women Returning to the Workforce, 1979; b. Recommendations on Unemployment Insurance, 1980; c. Submission to the CEIC Conference of Outreach Specialists 1980; d. Submission to the Standing Committee on Labour, Manpower and Immigration on the Proposed Amendments to Bill C-14, 1978; e. Summary, Problems of Immigrant Women in the Canadian Labour Force, 1979; f. Summary, Five Million Women by M. Proulx, 1978; and g. Women and Aging, by L. Dulude, 1978.

²² "71.6% of part-time workers are women, (and) 27.4% of women working for pay are unionized compared to 41.6% of men working for pay (1977)", CACSW Fact Sheet 1, Women and Work. See also J. White, Women and Unions, Ottawa: CACSW, 1980.

The effect on the embryo of the exposure of the male partner to carcinogens has also been under-researched. The assumption is too often erroneously made that women have the sole responsibility for producing healthy babies or conversely, unhealthy babies. Further, because women are the primary caretakers for children, they not only are given the guilt burden, but also the care burden for children who, because of exposure of the male partner to carcinogens,²³ develop transgenerational cancer or other developmental defects.

²³ Further discussion of these issues is found in the following books, which also contain extensive bibliographic reference:

"Forum - Women's Occupational Health: Medical, Social and Legal Implications", Preventive Medicine, Vol. 7, 1978, pp. 281-406.

L. Tataryn, Dying for a Living: The Politics of Industrial Death, Ottawa: Deneau & Greenberg, 1979;

S.S. Epstein, The Politics of Cancer, Garden City, New York: Anchor Press, 1979.

P. Kinnersly, The Hazards of Work: How to Fight Them, London: Pluto Press, 1973.

Canadian Advisory Council on the Status of Women, Position Paper on Reproductive Health Hazards in the Workplace, Ottawa: CACSW, 1980, (Further research currently underway).

A. Hricko with M. Brunt, Working for Your Life: A Woman's Guide to Job Health Hazards, Berkeley, California: Labour Occupational Health Program and the Public Citizen's Health Research Group, 1976.

A. George, Occupational Health Hazards to Women, Ottawa: CACSW, October, 1976.

V. Hunt, Work and the Health of Women, Boca Raton, Florida: CRC Press, 1979.

Breast Cancer: The Double Stigma

Cancer is the major cause of death in women between the ages of thirty-seven to fifty-five.²⁴ Breast cancer, the primary cause of cancer death in women aged thirty to sixty-nine, is diagnosed in one out of every fourteen Canadian women.²⁵ It is a disease which may herald a long period between onset and death, with devastating physical, economic and psychological complications for the woman and her family.

These problems are further exacerbated for women in a society which values highly the explicit sexual attractiveness and implied marketability of women. In addition to the stress factors brought to bear generally on relationships because of severe illness, extra stress might be brought on for a woman as the result of a husband/lover/boyfriend leaving because of his perceptions of the women's attractiveness, or as an indirect result of the woman's self-perception as less valuable and less valued.

²⁴ Boston Women's Health Book Collective. Our Bodies, Ourselves, 1979.

²⁵ The Canadian Cancer Society (1980) reports that the major causes of cancer death (total female and male) in Canada are, first, lung cancer, then cancers of the rectum and colon, and third, breast cancer. For women, breast cancer is the major cause of cancer death, followed by cancers of the rectum and colon, and then lung cancer. Projections, based on past increases in incidence of lung cancer in women, indicate that lung cancer may replace breast cancer as the leading cause of cancer death in women. This projection does not, of course, signal a decline in the rate of other cancers for women.

Let Women Decide

The medical professions have difficulties dealing with cancer as well. Doctors and nurses are human and they too have difficulty facing their mortality, as well as their inability to cure disease. They are loathe to relinquish the illusion that doctors know the patient's needs best and therefore they frequently circumvent the necessity for active patient participation in decision-making and patient monitoring of the quality of medical care.²⁶ Doctors may be reluctant to give cancer patients the information they ask for, particularly with regard to mortality statistics, prognoses and availability of services for crisis management.²⁷ They may fail to warn patients of possible side effects of recommended treatments or to discuss choices in drugs, radiation and surgery.

It has alternately been suggested by Vachon that patients may mis-hear medical information because of stress, as opposed to doctors blurring the information they transmit to patients. Rather than arguing polemically on this matter, it would be more useful to circumvent

²⁶ See, for example, M. L.S. Vachon "Women as Health Care Consumers". Presentation at Nurses' Association of American College of Obstetricians and Gynecologists, District V Conference, Ottawa, 1979, for a discussion of some of the factors leading to these medical attitudes on the part of physicians and nurses. See also E. Kubler-Ross, On Death and Dying, New York: MacMillan 1969, Chapter 11.

²⁷ The problem of mis-information is documented in Vachon et al, 1977, op.cit., p. 1153. "The three major areas our group of widows singled out for complaint were: (a) quality of nursing care, (b) accessibility of physicians and (c) accuracy of information".

both possible problems through written material. Literature outlining the nature of the disease, the prognosis, the methods of treatment available, and the side effects would be a reasonable starting point. Individualization of information then could commence on the premise that initial communication was clear. Perhaps additional techniques could be explored to ensure that the patient is hearing the information accurately, and the medical people are hearing the patient's concerns and directives accurately.²⁸

These failures in communication have had a widespread impact on women who may not receive information about such treatment alternatives as (and comparative prognoses of) radical mastectomies, modified radical mastectomies, and lumpectomies.²⁹ Women may also feel that they are in no position to question the sequence of events because they are frequently rushed into treatment with the advice that immediate action is required.³⁰

²⁸ For a patient's account of such events, see The Toronto Star, June 28, 1980, p. 1.

²⁹ For further discussion and references to such choices, see Boston Women's Health Book Collective, 1979, op. cit., pp. 128-135. Insistence by more women on fully informed consent and participation in treatment selection is discussed in M.L.S. Vachon, 1979, op. cit.

³⁰ In some cases, the reverse is true. Some women, on discovery of a breast lump through self-examination, receive premature reassurance from their doctors. In a Toronto study of women's perceptions of medical care for cancer, it was reported: "Most of the women who went to their doctors were treated appropriately but in 15% of the cases there is some concern about appropriate treatment in that the women were either reassured that everything was fine or were treated for non-malignant breast disease. As might be expected the recurrence and death rate was somewhat higher in this group (52% vs. 38% of women who received a biopsy or were sent for mammogram)." See M.L.S. Vachon et al, "The Relationship of Cancer Patients and Families to Physicians and the Medical System: A Psychological Perspective". Paper presented at the Annual Meeting of the College of Physicians and Surgeons of Canada, Montreal, February 1979, p. 2.

Doctors may also fail to suggest or plan for breast reconstruction when they have difficulty acknowledging the importance to some women of cosmetic and sexual considerations.

As one study documents,

"Rather than being told directly but in a supportive manner that they had breast cancer and would have to have further treatment, the women (in the study) were sometimes confronted with silence and mystery. Some of the women had great difficulty in even finding out their diagnosis, particularly if they had a lumpectomy. With a mastectomy the assumption of some surgeons was 'You never need to tell a woman she has breast cancer. She knows what it means when she wakes up without a breast.' With a lumpectomy or partial mastectomy, however, surgeons sometimes avoided telling the woman her diagnosis for a few days. This was most apt to happen if the physician and patient had pre-operative conflict about the most appropriate type of surgery. This lack of communication left the women frightened, angry and isolated and often resulted in defensive behaviour when they were presented for radiotherapy treatment."³¹

Pain Control

A final issue of great concern to cancer patients of both sexes is the problem of pain control. Again, this issue is complex. Most strong pain killers are addictive if administered in large doses over a long period of time and hospitals must maintain some control over use of addictive drugs.

However, the experience of many cancer patients has been that busy medical schedules and bureaucratic hospital systems can result in "forgetting" that a patient has requested or is due for pain-controlling medication, or may inhibit flexibility in frequency and strength of pain control for patients with different physical and psychological needs. As one patient reported:

³¹M.L.S. Vachon et al., Ibid., p. 3.

"For eight years I had sworn I would never become that supplicant person pleading - 'please - something for the pain - please!' I thought that my friends and I were smart enough, organized enough, together enough to beat the system. We weren't. We lost. For 23 painful hours. And I won't ever be quite the same again."³²

To avoid such situations, greater patient involvement in the administration of pain control could be encouraged. If patients were fully informed of the dangers and effectiveness of various types and dosages of pain medications, on the basis of this information and the particular characteristics of their cases, they could responsibly and more actively participate in the administration of pain relief drugs and drugs to combat the side effects of chemotherapy and other forms of treatment.

The short-term solutions to some of these problems are not complex. They involve such actions as the dispelling of myths through realistic dissemination of information, honest advertising campaigns, and truthful community education programs. They involve thorough consumer oriented assessments of the need for expanded or improved facilities for the treatment of cancer in Canada, and the consequent adoption of such routines as the flexibility of treatment hours to accommodate workers. The expansion of childcare and homemaker services is essential, as well as the realignment of philosophies and resources to facilitate good home care. New support for a broadened community advocacy network is required and is easily possible. Legislation which would ensure appropriate access to information and files by patients, and which would also ensure confidentiality and privacy from

³²

The Toronto Star, June 28, 1980, p. A8.

unauthorized persons, is required. Legislation which penalizes those who seek relief from pain and illness should be re-examined: the need is critical. Economic supports and commitments to minimize financial hardship must be selected and studies and increasing consumer advocacy in the health, social service and political systems of Canada must be instituted.

Long-term solutions necessitate planning for commitments of pure and applied research, for information sharing of research results, and for real attempts to encourage societal prevention of cancer. Until these questions are seriously addressed, women with cancer will continue to be imprisoned in situations of double hazard in Canada.

WOMEN AND PSYCHIATRIC ILLNESS

Psychiatric philosophy and response to women and mental health/mental illness have traditionally included assumptions, commentaries and judgements about women's adjustment to "natural" roles. Professional concern has focussed on the degree of a woman's acceptance of her "feminine nature", and on her acceptance, rejection or dissatisfaction with such "natural" events as motherhood.

This focus has been detrimental to all women but particularly to mothers. Mothers have traditionally been assumed to be almost solely responsible as transmitters, carriers or perpetrators of their children's schizophrenias, delinquencies or abused status; fathering roles are more neglected in psychiatric literature and more widespread societal factors are typically ignored.³³ We frequently hear that a woman's "natural" place is in the nuclear family raising the children. On the other hand, we know from historical and anthropological evidence, that infant mortality from neglect and abandonment was so widespread in England at the beginning of the Industrial Revolution that society moved toward assuming broadened social responsibilities for children.

Assumptions and judgements like these raise a number of relevant questions. Did the English Industrial Revolution make women who were mothers unnatural? And if it did, should they have received psychiatric care? In more "primitive" societies infants were cared for by a wide range of people, including young children and the aged, so that the mothers

³³For commentary upon psychiatric traditional beliefs about mothers, see M. Mead, Sex and Temperament in Three Primitive Societies, New York: Morrow, 1963, and R.P. Wortis, "The acceptance of the concept of the maternal role by behavioural scientists: its effects on women", in Women: Body and Culture ed. by S. Hammer, New York: Harper and Row, 1975, pp. 293-317.

could continue their essential food gathering, agricultural or hunting pursuits.³⁴ Was the role of women in these societies unnatural? And should they have received psychiatric care? Approximately half of all women in Canada, and that includes married women, are either working or looking for work.³⁵ Are the Canadian women in the labour force unnatural and in need of psychiatric help? Are the women not in the labour force unnatural and in need of psychiatric help? And do the myths and realities of a "woman's nature" affect the psychiatric treatment that women in Canada receive?

In a classic study of the attitudes of psychiatrists and psychologists (both female and male), a peculiar double standard of mental health was identified, "one for adult males and adult people, another for adult women. Should a woman change toward becoming a healthy adult, she becomes sick as a woman."³⁶ The potential impact of such attitudes upon women who are under psychiatric treatment signals the need to define value expectations about mental health workers who are in contact with women diagnosed as mentally ill, and the need to question many of the diagnoses of women as mentally ill.

³⁴ These examples are suggested by M. Mead, "A cultural anthropologist's approach to maternal deprivation" in Women: Body and Culture, S. Hammer (ed.), New York: Harper and Row, 1975. pp. 318-336.

³⁵ "46.3% of all married women are working or looking for work; 46.9% of all Canadian marriages have both husband and wife working (1976); working wives contribute about one-third of the family income (1976)", CACSW Fact Sheet 1, op. cit.

³⁶ The 1970 study by I. Broverman is discussed in most of the literature, including, for example, E. Robson and G. Edwards. Getting Help: A Woman's Guide to Therapy, New York: Dutton, 1980, p. 13.

Sixty percent of all admissions to public community psychiatric units in Canada are women.³⁷ Among the total admission figures, the most frequent diagnosis is neurosis,³⁸ allegedly behaviour that develops in an individual to ward off anxiety, but which paradoxically creates a whole spectrum of other problems. According to the same statistics, forms of neurosis most frequently suffered by Canadian women are depression, anxiety and

³⁷ Cardillo, Brenda, Psychiatric Discharges from non-psychiatric wards of general hospitals, 1975, Ottawa: Statistics Canada, 1980. Note that "public psychiatric units" are institutions recognized by each province as public, and are wards organized for psychiatric treatment within general hospitals. They are usually intended for short-term intensive treatment, and have a high turnover rate. The above report is based upon 1976 census figures and reports on 1975 hospital admissions. It does not differentiate, for example, between three separate admissions of three individuals versus one person admitted three times, although such differentiation would not affect the overall sex distribution at any given time. Studies of "the revolving door" syndrome, however, may identify treatment failure as opposed to individual "failure to get better".

³⁸ Among total admissions to both general and special hospitals/facilities, the most frequent diagnoses for women were neurosis (25%), schizophrenia (18%), alcoholism (15%) and affective neurosis (12%). Notable contrasts were observed in the diagnosis of alcoholism (23.7% of admitted men, 5.1% of admitted women), neurosis (33.6% of admitted women, 16.5% of admitted men), and affective psychosis (15.1% of admitted women, 8.3% of admitted men).

(From Statistics Canada, Special Care Facilities 1974, Ottawa: 1977 and Mental Health Statistics, Volume 1, Institutional Admissions and Separations 1976, Ottawa: 1979).

hysteria.³⁹ These statistics are, of course, only representative of some of our hospitalized women; they do not deal with women in other types of psychiatric institutions, or women under psychiatric treatment on a private or out-patient basis.⁴⁰

If a woman is diagnosed as depressed, a fairly likely diagnosis for her mental illness, her chances for inappropriate drug prescription by general practitioners and psychiatrists are higher than for men. If her adult activities are few, if she is socially isolated, and if her link to the job market is tenuous or non-existent, as is the case for more women than men in Canada, then her chances for mental illness appear higher than for less isolated women. If she is married, her chances for mental illness are higher still, and if she is past childbearing and child rearing age, her chances for hospitalization because of mental illness are at a peak.⁴¹

³⁹ 11,045 women were diagnosed as neurotic when receiving psychiatric help in Canada for the first time, and 9,778 re-admissions of women were diagnosed as neurotic, in 1976. Within this category, 8,869 were considered depressed; 1,255 anxious; and 329 hysterical. (Statistics Canada, loc.cit., 1977 and 1979)

⁴⁰ For a discussion of the problems inherent in mental health statistics in Canada, see D.E. Smith, "The statistics on mental illness: what they will not tell us about women and why", in D.E. Smith and S.J. David, (ed.) Women Look at Psychiatry, Vancouver: Press Gang, 1975, pp. 73-119.

⁴¹ See, for example, R. Cooperstock, "A review of women's psychotropic drug use" in the Canadian Journal of Psychiatry, Vol 24, No. 1, February, 1979, pp. 29-34 where she notes that between 67 and 72 percent of psychotropic drugs go to women.

On the basis of these indicators, preventive measures for women might include safeguards against irresponsible drug prescription, strengthened participation for women in the labour force, warnings against the risks of marriage and old age and programs to encourage expanded role options for women and men. Or, on the basis of these aforementioned indicators, the public, social, economic and psychiatric confusions that affect the rate at which women in Canada are judged to be neurotic, depressed, anxious or hysterical, could be re-examined, as could the manner in which their treatment evolves through psychiatric models and philosophies that reflect the very confusions which have compounded women's illnesses.

In Canada, there has already been initial discussion of the dangers inherent in a double standard of mental health, but the discussion is not yet broadly based and has not touched the majority of women's mental health judges; the teachers, counsellors, family doctors, psychiatrists, nurses, social workers, psychologists, ward attendants and after-cure workers who could make tangible contributions to increasing the level of mental health for women in Canada.⁴² Because the majority of these judges have not yet been reached, alternatives to the traditional psychiatric ethos have been developing slowly.

⁴² See E. Gede, "Women and Psychiatry", Atlantis, Vol. 4 No. 2, Part II, Spring, 1979, pp. 81-87, regarding the Canadian Psychiatric Association's Task Force on Women's Issues.

Support for information and referral centres run for and by women are required and in need of secure funding commitments. Support for community-based clinics and centres for women are obvious alternatives to traditional services and such centres require evaluations conducted in conjunction with the consumer.⁴³ With such supports there can be an initiation of systematic and committed attempts to clarify areas of confusion, to dispel myths and to provide preventive and community education options for Canadian girls and women, for their mothers and for their grandmothers. An easing of the distinctions between the judged and judges, a re-examination of the impact of sex roles and myths on women's mental health, and support for alternative treatment and after-care programs in conjunction with a preventive approach will lead us to a society which strengthens the humanity of women and men.

⁴³ See, for example, O. Lockey, "Feminist Services and Research Mental Health Collectives: Cooperation for Survival" in Atlantis, Vol. 4, No. 2, Part II, Spring, 1979, pp. 128-132, and D.E. Smith and S.J. David, ed., 1975, op. cit.

MOTHERS OF CHILDREN WITH HANDICAPS

Although change is occurring with regard to child care roles in some Canadian homes, the major responsibility for child care still falls on the mother, as does the responsibility for perceived failures in providing appropriate parenting. Most Canadian women who have been mothers of young children are aware of squeezing in job demands, factory shifts and report deadlines while planning children's dentist appointments, school, camp and babysitting schedules; of keeping track of daily tasks while trying to seek out moments of friendship and solitude.

A mother of a handicapped child is likely to encounter many additional demands. At the time of initial diagnosis - in the maternity ward or in the principal's office - there may be no information, guidance or practical help available. The woman begins a career as information seeker and child advocate within the confines of her role as a mother of a handicapped child, while carrying the extra demands that a handicapped child may impose.

She is more likely to experience marital stress,⁴⁴ and if she is a single parent her chances for a reasonable income are low, lower still if her child needs special diets, special equipment, and special transportation. If she cannot obtain regular babysitting or occasional

⁴⁴ See, for example, R.H.A. Haslam, "Rights of the handicapped or defective infant" in Canadian Pediatric News Bulletin Supplement, Vol. 10, No. 5, 1979, for a review of the studies of stress factors on families and marriages where a spina bifida child is cared for within the family.

parent relief services, her chances for depression are high, and are further heightened by the knowledge that no one can or will, temporarily substitute for her. If she has no reasonable assurance that appropriate community facilities exist for her growing child, if she is forced to consider institutionalization of her child, if she has no implicit or explicit assurance that her child's rights will be protected throughout adolescence and adulthood, her chances for depression are higher still. If she is simultaneously trying to locate a decent school for her child, fend off discrimination directed toward her ethnic status, protect her other children from neighbourhood stigma, resolve her re-entry into the job market with shattered self-confidence, live with no assurance of adequate pay, pensions or unemployment insurance coverage and with no adequate daycare provisions, her chances for depression are guaranteed.

If she remains too poor to afford home ramp construction for her child's wheelchair, her chances of back injury from lifting her child are high. If she is depressed or on a limited income, her chance for nutritional deficiencies are high. If her agency or mental health worker implies that she is rejecting her child or rejecting her feminine nature, her chances for insanity are high. If a parents' organization for the handicapped is unaware of her needs, or if her opportunities for self-assistance are diminished by political decisions, she becomes a silent Canadian non-statistic.

It is important to observe that some parents have collectively and formally been able to wrest supports or services for their children and themselves. Groups

such as Canada's local associations for the mentally retarded are primarily responsible for the very existence of classrooms and schools that their children can finally enter after a long history of exclusion, and these organized associations have been more effective than most parents' groups in advocating for such changes. They are also, however, fairly bureaucratic structures in many cases, with large budgets and conflicting responsibilities for both service delivery and advocacy. Consequently the "grass roots" nature of supports available to their members has gradually faded.

In response to the gradual withdrawal of supports, some parents have collectively and informally been able to offer each other critical support. Canada is witnessing the quiet and spontaneous development of "underground" parent groups. Some of these groups are lobbying for structural and philosophical changes within the more formal associations, while others ignore the formal associations and develop their own support systems and advocacy priorities. Some have formed when parents of pre-school children have met together and shared experiences of the treatment they received in Canadian maternity wards, and their subsequent frustrations. Most of these groups are small, but they provide moral support, emergency or family relief, and exploration of imaginative responses to situations where their children are excluded. They are also becoming adept at the process of monitoring services and effectively directing improvements in the quality of life for their mentally retarded children and for each other.⁴⁵

⁴⁵ W. Wolfensberger. The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded. Downsview, Ontario: National Institute on Mental Retardation, 1973.

To reassert the value of parenting, and the need for appropriate care for children with handicaps, the efforts of these parents should be strongly supported and the directions they have indicated followed.

CONCLUSION

To affirm equality and full citizenship for all Canadians, including the retarded person, the individual with cancer, the woman diagnosed as mentally ill, the parent of a handicapped child, initiatives must be taken along many dimensions including human rights, socio-economic, advocacy, education, information, health and social service dimensions.

Some possible directions for action within these dimensions which might be initiated through the Special Committee on the Disabled and the Handicapped, are attached. (See Appendix) These represent the opinions of the authors. CACSW recommendations will be submitted following detailed consideration of this brief by the CACSW committee on health.

While these directions outline only a partial solution to the dilemmas of women with handicaps, they emphasize that any attempt to lessen the problems of the handicapped must include increased research and information sharing, and widespread participatory prevention. It should involve an effort to better comprehend how educational objectives, funding priorities, legislation, political decisions and social policies affect women with handicaps. An effective concern with women with handicaps must include above all, a commitment to affirm the humanity, dignity and integrity of all Canadians.

APPENDIX I

DIRECTIONS FOR CHANGE

The Human Rights Dimension

1. Conduct a systematic legislative review of the status of handicapped and disabled people in Canada, to identify exclusions or inappropriate inclusions pertaining to human rights issues, and to suggest changes sensitive to the special problems of handicapped women. Legislation regarding institutionalization, (including public and private psychiatric and custodial institutionalization), patient accessibility to files and records, the relief of pain and suffering and sterilization might be included in this review.

The Socio-Economic Dimension

1. Identify the economic and social burdens carried by parents (particularly mothers and single parents) of handicapped children, and women/men caring for husbands, wives, parents and other relatives in the home. This study would be the base for the development of preventive and ameliorative supports, planned with the help of women/men who have accepted this unofficial care role.
2. Develop a more equitable income base for the handicapped and the disabled, including the elderly, paying particular attention to the double economic hazard of women with handicaps.

3. Improve availability of good quality childcare, to provide more equitable access to the labour force for mothers and/or single parents of handicapped as well as non-handicapped children.

The Advocacy Dimension

1. Provide for effective representation of the handicapped and proportional representation of women and men with handicaps on boards, commissions, agencies, committees, etc. concerned with the handicapped, or with issues which will have significant impact on a portion of the population with handicaps.
2. Develop effective support/advocacy networks for women with cancer and other "invisible" handicaps, in conjunction with community-based groups and organizations.
3. Support community-based information and referral centres, mental health counselling, and treatment centres developed by women for women with psychiatric illness. These centres could play an important part in developing preventive and community education options for Canadian girls and women in relation to mental health.
4. Utilize the expertise of feminist groups and centres including their personnel, publications, libraries and consultative resources, in monitoring actions, debates and decisions pertaining to women with handicaps.

The Education Dimension

1. Encourage truthful advertising and widely based public education to dispel myths about cancer; develop and share accurate information on the nature of cancer, its prognoses, methods of treatment and side effects.

The Information Dimension

1. Encourage a more reliable national data collection system of many groups of people with handicaps including sex, age, diagnostic breakdowns, and proportions of each group confined to institutions.
2. Undertake a study on the adequacy of emergency care, alternate emergency systems, the length of short and long term waiting lists for diagnostic, treatment and emergency care and the average waiting periods for patients for such care.

The Social Service Dimension

1. Provide non-institutional homes for the majority of women and men with single or multiple handicap, and encourage the move away from total institutions through a transfer of funding from institutions to the community.

The Social Service Dimension (cont'd)

2. Provide special services through existing Planned Parenthood Centres to counsel retarded adolescents and adults, and their parents where appropriate, on birth control options and on dealing with the sexuality of a retarded family member.

The Health Dimension

1. Ensure competent and ongoing preventive and ameliorative care for all inmates in Canadian institutions.
2. Enquire into and regulate, where appropriate, the use of such drugs as Depo-provera in Canada.
3. Examine ways and means of protecting women from inappropriate drug prescription, with specific reference to psychotropic drugs.
4. Encourage self-examination of attitudes of medical/health professionals towards women with handicaps during orientation, professional training and in-service programs utilizing the expertise of feminist groups and resources.
5. Undertake further study to broaden understanding of how cancer affects women, including the socio-economic and medical systemic factors which may exacerbate illness; and to suggest preventive and ameliorative approaches to the identified factors.

The Health Dimension (cont'd)

6. Support and encourage research, both pure and applied, that might aid in identifying occupational and environmental health hazards, including carcinogens, in Canada.
7. Conduct nationwide inventories of cancer facilities, including actual capacity and waiting list data for diagnostic, treatment, emergency care and palliation services; establish the availability of psychological, nutritional and physiotherapeutic supports to alleviate identified problems such as under-staffing, insufficient treatment spaces and hours, and over-crowding of such facilities and services.
8. Examine the hospice philosophy, suggesting networks to facilitate home care backed up by easily accessible palliation units, to avoid repetition of private industry's exploitation of need for such service in the United States and to ensure that a legitimate palliation philosophy is actually practiced and maintained. Safeguards here would include patient and family evaluation as part of monitoring studies of palliative care; and adequate provision of such services to accommodate Canadian needs in this regard. Time constraints did not permit inventories of hospice networks and palliation units across Canada by the authors of this brief, and the Special Committee on the Disabled and the Handicapped may wish to conduct or second such study following the anticipated report of Health and Welfare's Subgroup on Palliative Care Services

The Health Dimension (cont'd)

(8.)

of the Working Group on Special Services in Hospitals, staffed by an inter-disciplinary group of professionals in the field. This study on standards of palliative care could well be shared with consumer and professional interest groups concerned with Canadian palliation services.

TABLE I

1976 INCIDENCE AND MORTALITY STATISTICS
FOR ALL CANCERS IN CANADA,
BY AGE AND SEX

Age	Incidence *		Mortality **	
	Female	Male	Female	Male
Not stated	3	8	37	39
Under 1 yr.	11	20	5	7
1-4	39	56	33	53
5-9	28	50	50	67
10-14	53	59	44	59
15-19	89	98	56	94
20-24	158	166	61	100
25-29	260	178	84	110
30-34	406	267	145	128
35-39	587	336	260	191
40-44	869	540	392	375
45-49	1 422	1 014	777	708
50-54	1 976	1 703	1 201	1 258
55-59	2 398	2 266	1 488	1 813
60-64	2 609	3 188	1 866	2 585
65-69	2 540	3 471	1 930	3 012
70-74	2 178	3 367	1 965	3 128
75-79	1 862	2 589	1 869	2 540
80-84	1 390	1 803	1 534	1 835
85+	1 187	1 385	1 492	1 387
Total	20 065	22 564	15 289	19 489
Female & Male Total	42 629			

* Source: Statistics Canada, Catalogue 82-207, Cancer in Canada 1976, 1979, page, 2 Table 1.

** Source: Statistics Canada, Catalogue 82-207 Cancer in Canada 1976, 1979, page 72, Table A

Note that some of Statistics Canada figures are incomplete because Ontario has only recently begun to supply Statistics Canada with Ontario figures, so that published data is not yet fully representative of Canadian incidence and mortality rates for cancer.

BIBLIOGRAPHY

Accardo, P.J. and Capute, A.J. The Pediatrician and the Developmentally Delayed Child: A Clinical Textbook on Mental Retardation. Baltimore: University Park Press, 1979.

Boston Women's Health Book Collective. Our Bodies, Ourselves. Rev. ed. New York: Simon and Schuster, 1979.

Canadian Advisory Council on the Status of Women:

- a) Position Paper on Reproductive Health Hazards in the Workplace. Ottawa: 1980.
- b) Recommendations on Unemployment Insurance. Ottawa: 1980.
- c) Recommendations on Women Returning to the Workforce. Ottawa: 1979.
- d) Submission to the C.E.I.C. Conference of Outreach Specialists Ottawa: 1980. (Unpublished).
- e) Submission to the Standing Committee on Labour, Manpower and Immigration on the Proposed Amendments to Bill C-14, an Act to Amend the Unemployment Insurance Act. Ottawa: 1978. (Unpublished).
- f) Summary, Problems of Immigrant Women in the Canadian Labour Force. Ottawa: 1979
- g) Women and Aging. Fact Sheet No. 2. Ottawa: 1979.
- h) Women and Work. Fact Sheet No. 1. Ottawa: 1979.

Canadian Association for the Mentally Retarded. Questions and Answers About Mental Retardation. Downsview, Ontario: 1979.

Cardillo, Brenda. Psychiatric Discharges from Non-psychiatric Wards of General Hospitals, 1975. Ottawa: Statistics Canada, 1980.

Cooperstock, R. "A review of women's psychotropic drug use". Can. J. of Psychiatry, 24(1), 1979, pp. 29-34.

Dowsling, J. and MacLennan, A., eds. The Chemically Dependent Woman. Proceedings of a Conference Sponsored by the Donwood Institute, Toronto, 1977. Toronto: Addiction Research Foundation of Ontario, 1978.

Dulude, L. Women and Aging: A Report on the Rest of Our Lives. Ottawa: Canadian Advisory Council on the Status of Women, 1978.

Epstein, S.S. The Politics of Cancer. Garden City, New York: Anchor Press, 1979.

"Forum - Women's Occupational Health: Medical, Social and Legal Implications". Preventive Medicine, 7, September, 1978, pp. 281-406.

Fraser, J. The Female Alcoholic. Toronto: Addiction Research Foundation of Ontario, 1976.

Gede, E. "Women and Psychiatry". Atlantis, 4(2), Part II, Spring, 1979, pp. 81-87.

George, A. Occupational Health Hazards to Women. Ottawa: Canadian Advisory Council on the Status of Women, 1976.

Goffman, E. Asylums: Essays on the Social Situation of Mental Patients and Other Inmates. New York: Doubleday, 1961.

Hammer, S., ed. Women: Body and Culture. New York: Harper and Row, 1975.

Haslam, R.H.A. "Rights of the handicapped or defective infant". Canadian Pediatric Society News Bulletin Supplement, 10(5), October/November, 1979.

Health and Welfare Canada. Disabled Persons in Canada. Ottawa: Supply and Services Canada, 1980.

Hricko, A. with M. Brunt. Working for Your Life: A Woman's Guide to Job Health Hazards. Berkeley, California: Labour Occupational Health Program and the Public Citizen's Health Research Group, 1976.

Hunt, V. Work and the Health of Women. Boca Raton, Florida: CRC Press, 1979.

Kinnersly, P. The Hazards of Work: How to Fight Them.
London: Pluto Press, 1973.

Kubler-Ross, E. On Death and Dying. New York: Macmillan, 1969.

Levine, C. "Depo-provera and Contraceptive Risk: A case study of values in conflict". The Hastings Centre Report, 9(4), August, 1979, pp. 8-11.

Lockey, O. "Mental Health Collectives: Cooperation for Survival". Atlantis, 4(2), Part II, Spring, 1979, pp. 128-132.

MacLennan A., ed. Women: Their Use of Alcohol and other Legal Drugs. Toronto: Addiction Research Foundation of Ontario, 1976.

MacLeod, L. Wife Battering is Every Woman's Issue. A summary report of the CACSW consultation on wife battering, March 5-7, 1980. Ottawa: Canadian Advisory Council on the Status of Women, 1980.

Mead, M. Sex and Temperament in Three Primitive Societies. New York: Morrow, 1963.

Ontario Legislature Debates. 4th Session, 31st Parliament, June 2, 1980, Standing Committee on Social Development, No. S-19, p. S 572.

Proulx, M. Five Million Women. Ottawa: Canadian Advisory Council on the Status of Women, 1978.

Robson, E. and Edwards, G. Getting Help: A Woman's Guide to Therapy. New York: Dutton, 1980.

Smith, D.E. "The Statistics on Mental Illness: What They Will Not Tell Us About Women and Why". Smith, D.E. and David, S.J. Women Look at Psychiatry. Vancouver: Press Gang, 1975, pp. 73-119.

Sontag, S. Illness as Metaphor. New York: Random, 1977.

Statistics Canada:

- a) Cancer in Canada 1976. Ottawa: 1979.
- b) Mental Health Statistics, Volume I, Institutional Admissions and Separations, 1976. Ottawa: 1979.
- c) Perspectives Canada III. Ottawa: 1980.
- d) Special Care Facilities 1974. Ottawa: 1977.

Tataryn, L. Dying for a Living: The Politics of Industrial Death. Ottawa: Deneau and Greenberg, 1979.

The Globe and Mail:

- a) (Depo-provera). July 23, 1980, p. 12.
- b) "Retarded should be sterilized, parents say". March 25, 1980.

The Toronto Star "I lost control of my own life". June 28, 1980, pp. 1,8.

Vachon, M.L.S. "Women as Health Care Consumers". Paper presented at the Nurses' Association of the American College of Obstetricians and Gynecologists, District V Conference. Ottawa: 1979.

Vachon, M.L.S., Freedman, K., Formo, A., Rogers, J., Lyall, W.A.L. Freeman, S.J.J. "The final illness in cancer: the widow's perspective". Canadian Medical Association Journal, 117(10), November, 1977, pp. 1151-1154.

Vachon, M.L.S., Rogers, J., Cochrane, J., Lyall, W.A.L. and Freeman, S.J.J. "The Relationship of Cancer Patients and Families to Physicians and the Medical System: A Psychological Perspective". Paper presented at the Annual Meeting of the College of Physicians and Surgeons of Canada. Montreal: 1979.

White, J. Women and Unions. Ottawa: Canadian Advisory Council on the Status of Women, 1980.

Wolfensberger, W. The Principle of Normalization in Human Services. Downsview, Ontario: National Institute on Mental Retardation, 1972.

Wolfensberger, W. The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded. Downsview, Ontario: National Institute on Mental Retardation, 1973.

Wortis, R.P. "The acceptance of the maternal role by behavioural scientists: its effects on women". In Women: Body and Culture. Edited by S. Hammer. New York: Harper and Row, 1975.

